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ABSTRACT

This final report describes activities and accomplishments of a four-year federally funded project in Illinois to provide technical assistance to agencies and organizations providing early intervention, educational, transitional, vocational, and related services to children with deaf-blindness. The project supported the activities of deaf-blind specialists throughout the state in their work with local school programs and community service providers. Information brochures, periodic telephone contacts, and training on various related topics were offered to these specialists. Presentations were made at state-wide conferences. Specialists conducted student evaluations and needs assessments of professionals and family members. The project also developed a training videotape and inservice training modules based on those content areas most frequently identified in needs assessment surveys. Specific accomplishments are listed for each of the project's seven goals: (1) technical assistance child identification request for services; (2) technical assistance needs assessment; (3) technical assistance service plan; (4) technical assistance empowerment of families; (5) technical assistance resource center; (6) technical assistance evaluation; and (7) technical assistance dissemination. A case study illustrates the project's impact. Appendices present two charts which summarize specialists' activities and state geographic assignments for specialists. (DB)

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ED 436 914

SERVICES FOR CHILDREN WITH DEAF-BLINDNESS
ILLINOIS STATE PROJECT

FINAL PERFORMANCE REPORT

PROJECT NUMBER: H025A50047

PROJECT START DATE: October 1, 1995
PROJECT END DATE: September 30, 1999

PROJECT TITLE: Illinois State Project: Services for Children with Deaf-Blindness Program

GEOGRAPHIC AREA SERVED: Illinois

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Services for Children with Deaf-Blindness
Program – Illinois State Project

Final Report (FY 96, FY 97, FY 98, FY 99)
December, 1999

I. Executive Summary

The *Illinois State Project: Services for Children with Deaf-Blindness Program* provided technical assistance to public and private agencies, institutions and organizations providing early intervention, educational, transitional, vocational, early identification and related services to children with deaf-blindness. Technical assistance was designed to assure that service providers may more effectively provide special education services; provide inservice training to paraprofessionals and professionals; provide activities to facilitate parental involvement; provide consultative services; and promote the integration of children with deaf-blindness with children with other disabilities and without disabilities. Services were coordinated with other state agencies responsible for providing services to children with deaf-blindness.

The Illinois project supported the activities of deaf-blind specialists who live and work in the different strategic geographic areas of the state. These specialists work with local school programs and community service providers to identify and provide technical assistance to children (ages birth to 21). Information brochures, periodic telephone contacts, and trainings on a variety of related topics were offered to program staff. Presentations were made at statewide conferences as a way to inform special education personnel and community service providers about the issues of deaf-blindness, services available, and to increase the identification of eligible children and those suspected of having dual sensory impairments. Specialists conducted informal functional vision and hearing evaluations. They assisted in the process of making referrals for formal diagnostic evaluations. Needs assessments were distributed to family members and professionals which allow them the opportunity to identify areas of need for consultation services and various forms of technical assistance. Areas most frequently noted on completed needs assessments were: functional curriculum, communication, behavior management, vision information, hearing information, orientation and mobility, transition, integration/inclusion, and instructional best practices. Technical assistance was requested in all areas of curricular domains. The project developed a training video tape and inservice training modules organized by content areas most frequently identified on completed needs assessment surveys.

II. Project Description

Goal 1.0: Technical assistance child identification request for services

1.1 Identify children residing in Illinois between the ages of birth and twenty one who have significant impairments in both vision and hearing.
1.2 Disseminate information describing the project to those in need of the offered services.
1.3 Describe referral process for accessing project services.
1.4 Establish child data base for storage, retrieval and management of individual specific information.

Goal 2.0: Technical assistance needs assessment

2.1 Update needs assessment instrument as a vehicle to identify specific need requests for technical assistance.
2.2 Identify administration method to be used with the needs assessment.
2.3 Analyze data as submitted on the needs assessment form.

Goal 3.0: Technical assistance service plan

3.1 Hire regional specialists with expertise and training in the area of deaf-blindness technical assistance.
3.2 Prioritize needs for the individual requesting technical assistance.
3.3 Review resource options to determine appropriate method to meet targeted needs.
3.4 Develop service plan to meet targeted needs.
3.5 Plan for interagency collaboration with Illinois state code agencies and statewide technical assistance service providers.
3.6 Plan annual conference with IAC on topics related to the field of deaf-blindness based on needs assessment information.

Goal 4.0: Technical assistance empowerment of families

4.1 Assist family organization development for parents and family members with a child who is deaf-blind.
4.2 Plan family weekend training for 40 families.
4.3 Develop information products for families.

Goal 5.0: Technical assistance resource center.

5.1 Develop training materials to supplement the Philip Rock Center Resource Center.
5.2 Translate materials to Braille, large print or Spanish upon request.
5.3 Create americans with disabilities act file from gathered materials to have resource pool of information available upon request.

Goal 6.0: Technical assistance evaluation

6.1 Identify purposes of evaluation.
6.2 Select design for evaluation process.
6.3 Implementation evaluation design selected for the specific activity.
6.4 Review by Illinois Advisory Board for Services for Individuals who are Deaf-Blind.

Goal 7.0: Technical assistance dissemination

7.1 Target audiences to receive project activities information.
7.2 Develop formative reports to be disseminated statewide.
7.3 Develop summative reports to be disseminated statewide.

III. Context

The purpose of the Illinois State Project was to provide individual technical assistance, information, and training to address the early intervention, special education, related services, and transition service needs of children with deaf-blindness and enhance state capacity to improve services and outcomes for children and their families. Technical assistance was designed to assure that service providers more effectively provide special education services, provide inservice training to paraprofessionals and professionals, provide activities to facilitate parental involvement, provide consultative services, and promote the integration of children with deaf-blindness with children with other disabilities and without disabilities. Activities were coordinated with other state agencies responsible for providing services to children who are deaf-blind.

The project goals addressed the need for technical assistance with a statewide coordinated and collaborative approach to the following areas for children and youth who are deaf-blind: Child Identification/Request for Services, Needs Assessment, Technical Assistance Service Plan, Empowerment of Families, Resource Center, Evaluation and Dissemination.

The project supported the activities of four deaf-blind specialists in the different strategic geographic areas of the state. Project staff worked with local school programs, families, and community service providers to identify and provide technical assistance to children (ages birth to 21). Based on the needs identified in the literature and through the Illinois needs assessment process, the project technical assistance plan was designed to make a positive impact on system change and improve services for children who are deaf-blind.

IV. Accomplishments

A. Goal 1.0: Technical Assistance Child Identification Request for Services

Census

The project requires documentation of hearing and vision losses based on diagnostic information (i.e., audiological and ophthalmologic) and support for acquiring those evaluations. The referral and identification of children who are deaf-blind is 425. These efforts have brought the Illinois census closer to the nationally projected 537 count figure for the State. These efforts are enhanced by the ongoing work of the Usher Screening committee which has increased early identification of students with Usher Syndrome increasing numbers of students who are listed on the deaf-blind census.

Early Intervention

Deaf-Blind Specialists connected families with other Part C providers, dealt with safety issues, and provided transportation to services. Specialists attended local interagency council meetings, and linked families and service providers with community resources. Project staff offered new service providers the skill training necessary to work with children who are deaf-blind and their families. One of the primary roles staff members served was to assist families and children with the transition from a) birth to two programs, to pre-school programs and services, and b) pre-school programs to school.

B. Goal 2.0: Technical Assistance Needs Assessment

Needs Assessment

A state shareholders meeting was conducted to bring together representatives from a cross section of service providers and parent representatives. This group reviewed needs assessment data compiled from annual collection statewide and prioritized areas of training for follow-up. Based on areas of needs identified training was scheduled on the topics of: "Overview of Deaf-Blindness", "Behavior Management", "Orientation and Mobility", "Communication" and "Transition".

C. Goal 3.0: Technical Assistance Service Plan

Expertise and Qualifications

The project was staffed by a project director, based in the Illinois State Board of Education; a project coordinator who also serves as the chief administrator of the Philip Rock Center and School: deaf-blind specialists and a service center secretary. The project was housed at the Philip Rock Center and School in Glen Ellyn, Illinois. The deaf-blind specialists were based within the geographic regions that they serve, allowing efficient access to direct technical assistance and effective coordination with other local and state service delivery systems. Advantages to being housed at the Philip Rock Center included: 1) being

geographically located near the primary population base; 2) the ability to learn from and share resources with the students and staff members at Philip Rock School; and 3) the ability to attend student IFSP and IEP meetings.

The background and skills of staff members represent a balance of expertise in the areas of vision, orientation and mobility (O & M), hearing loss, and severe multiple disabilities. Ongoing staff development opportunities (e.g., Technical Assistance Team) and the ability and willingness to cross train between staff members has enabled each of these individuals to acquire excellent technical skills applicable to the unique needs of learners who are deaf-blind. Consultants are used when specific areas of expertise are needed, and also serve as an additional training opportunity for project staff members. The longevity of project staff members has allowed for relationships and trust to develop and for consistent support to available for families and service providers in the field.

TA System

Project staff members have developed several forms to formalize the TA process including two needs assessments (one for families and one for professionals), a Technical Assistance Service Plan, a process for sharing calendars, and Contact Summary Forms. The needs assessment also served as a request form, indicating both the area of need (content) and the desired type of assistance (format). Specialists responded to each request through phone contact, on-site consultation, distribution of materials, or other means. Needs assessment information also was used to identify high priority needs across individuals and agencies, to develop training opportunities and materials (e.g., workshops, topical information) around these topics. For example, high priority need in the area of vision, led to the development of the vision training video.

Written technical assistance procedures for documenting the process of providing technical assistance from initial referral/request for assistance through evaluation and closure and have been developed. Procedures included a narrative specifying: 1) how TA is requested by service providers and families; 2) criteria for selecting/prioritizing TA requests; 3) how initial plans are developed (including how training and TA will be delivered and how resources will be allocated); 4) how follow-up will occur, 5) how each TA activity is evaluated; and 6) what is expected from the TA recipient prior to further TA from the project.

LRE and Inclusive Education

The Illinois Board of Special Education, has identified the integration of students with severe disabilities as a priority in the State Plan. Project CHOICES (Children Have Opportunities in Inclusive Community Environments and Schools), and Illinois least restrictive environment initiative has been in existence since 1988. The Philip Rock Center and School worked in collaboration with

Project CHOICES early on enabling the successful transition of Philip Rock School students into classrooms within the local education agency.

While at this time, very few children who are deaf-blind in Illinois receive education in general education settings, it is clearly a priority at the state level. It is likely that as schools become more accustomed to accommodating a diverse student body, an increasing number of parents and professionals will be looking to the deaf-blind project for providing information on how to adapt the general education curriculum and environment for students who are deaf-blind.

Commitment to the Provision of Technical Assistance

This project did an outstanding job of providing direct, consistent, and frequent technical assistance to consumers and families. The number of contacts with technical assistance recipients, whether by written reports, on-site visits, or phone consultation is indicated on Chart A. The variation of technical assistance is based directly on needs identified by all recipients and include, but are not limited to: training sessions provided on a regional basis, on-site consultations, dissemination, diagnostics and referrals, and connection to community and state providers not necessarily related to deaf-blind (e.g., funding, doctors, specialists, or services). Consumers have indicated high degrees of satisfaction with all TA activities as evidenced by consumer satisfaction data and phone interviews. The members from the IL Deaf-Blind Advisory Council and the IAC committee highly praised the quality of staff members and IADB members recognized the outstanding service provided by the IL Deaf-Blind Project.

Transition

Project staff members met monthly with two different interagency groups (the Interagency Agreement Committee and the Illinois Advisory Board of Services for Persons who are Deaf-Blind), allowing many opportunities to network and dialogue with adult service agencies regarding a broad range of services. However, concerns regarding the early involvement of adult service representatives in transition planning and IEP meetings continue. As in most states, limited funding, and large caseloads of adult service providers discourage them from early, active involvement in transition planning.

Case studies and stories of the struggles experienced by students who have left school already are being collected and share as evidenced by the document, Portraits of Isolation: Current Status of Illinois Citizens who are Deaf-Blind.

D. Goal 4.0: Technical Assistance Empowerment of Families

The project has a strong emphasis on family centered services. The Illinois Deaf-Blind Project has been instrumental in providing the leadership and financial support needed to mobilize the newly formed parent organization, the Illinois

Advocates for the Deaf-Blind (IADB). Annual family weekends, scheduled and conducted to accommodate the unique needs of families, was a priority activity. Parents and other family members also are invited and encouraged to participate in all training and technical assistance activities. A web site was established for IADB on the internet.

Project staff members have disseminated a needs assessment specifically for parents, which takes into account the unique needs of families in user friendly format. An 800 phone number (Voice/TTY) has been established and many project materials have been translated into Spanish to assist parents access project resources and services. Project staff members have been very creative in accommodating families who native language is other than English or Spanish, such as linking with LEAs or other agency activities in which interpreters are available.

Family satisfaction with services provided by the project is very high as evidenced by evaluation data.

E. Goal 5.0: Technical Assistance Resource Center

Resources and Products

The project has developed many quality products and resources that are accessible in alternative forms of media and available in Spanish. These products include, but are not limited to:

- 1-800 number in Voice and TTY available to consumers statewide
- loan library containing literature, books, toys, assistive technology, and adaptive equipment (toys and assistive technology are specifically matched to individual requests)
- information packets and fact sheets
- IAC Resource Book
- Portraits of Isolation: Current Status of Illinois Citizens Who Are Deaf-Blind
- Project descriptions and packets
- Brochures
- Guidelines for Working with Deaf-Blind People
- newsletters
- Usher Syndrome screening materials
- "Do you See What I See? Helping Young Children with Vision Impairments Develop Sight" – Parent training (video tape)

F. Goal 6.0: Technical Assistance Evaluation

Evaluation

The evaluation plan contains five levels of evaluation consisting of frequency, satisfaction, knowledge/skill acquisition, knowledge/skill implementation, and

child change. There is evidence regarding frequency of contacts and types of technical assistance documented on the monthly progress summary sheets and satisfaction evaluation data collected for every training session and meeting. Additionally, extensive anecdotal records are available indicating that children receiving technical assistance have increase access to their environment and to the significant people in their lives.

G. Goal 7.0: Technical Assistance Dissemination

Dissemination

There is ongoing coordination and collaboration between other state, national, and community agencies and the Illinois Deaf-Blind Project. Staff members reported ongoing relationships and collaborative efforts with the following agencies, such as:

- HKNC-affiliate program
- NTAC support for training workshops
- IL Assistive Technology Project and activities
- StarNet in the coordination of birth to age eight services
- IL School for the Deaf (site visits, presentations, family weekends, and summer institutes)
- IL School for the Visually Impaired (site visits, parent-infant institute, and referrals)
- Helen Keller Regional Center Representative (working on placement of a student at Sands Point)
- IL Interagency Agreement Committee (IAC)
- IL Advisory Board for Services for Persons who are Deaf-Blind reporting to the Governor and General Assembly on issues pertaining to deaf-blind
- Child and Family Connections
- Northern Illinois University (development of instructional videotape relating to vision assessment)

Data was collected on who was using resources and products, what resources and products were most frequently requested, and what particular products consumers found useful. The project computerized its loan library and now has a system to keep accurate records on library use. Additionally, project visibility is increased by accessing different audiences not typically addressed by deaf-blind projects.

Staff members seek additional audiences by displaying project brochures, information, and products at special education directors' meeting, school nurses' conferences, association of superintendent's conferences, and other discipline areas' meetings and conferences.

V. Lessons Learned

The following case study illustrates the impact of the technical assistance provided by the project.

CASE STUDY

Feb, 1997 - 9 months old boy - parents call PRC at suggestion of county health nurse. During initial visit February 25, vision and hearing screening are completed. Vision skills were well below developmental levels. He was able to look at lights in the center and left, but he had difficulty looking to the right, up, and down. He could follow a moving light from center to right and back. He did not look at unlit objects. He would stop moving when sounds were presented 2 feet from left ear, but not right ear. He did not turn to sounds. He was referred to DSCC (Department of Specialized Care for Children) for financial assistance with medical costs (he had no insurance). Medical vision and hearing testing were done at that time. When medical records were obtained a visually evoked response test showed delay in both optic nerves' ability to conduct stimulus from the eyes to the brain. An eye examination showed wandering nystagmus (constant and involuntary movement of the eyes), as well as myopia and astigmatism. An auditory evoked response test showed delay in the auditory nerves' ability to conduct stimulus from the ears to the brain. It was unsure if the visual and auditory conduction problems were permanent due to central nervous system issues, or temporary, due to immature mylenation. No clear medical diagnosis besides microcephaly, so he was not admitted to the DSCC program. He was approved for general developmental services and speech and language therapy from Marklund Early Intervention. He was made eligible for Philip Rock Center Deafblind services in May 1997 after medical reports confirmed eligibility. His family requested both technical assistance from a Deafblind Specialist and Developmental Therapy from a Child Development Specialist.

Developmental Therapy Services. At first provided 2x month, April 98 switched to 1x week as other therapies were discontinued due to funding issues. Goals have included 1997: signaling for more of a body movement game by moving the associated body part, alerting to more and localizing (turning towards) sound, visual tracking and scanning.
1998: discriminating pictures, participating in group interactions, strengthening muscles, use a device to signal, and wearing hearing aids.

Now: Since being assessed in September, he has mastered: recognizing an object even if he only sees part of it, examining new objects by manipulating them, locating objects in the place they are customarily kept, anticipating routine events from visual, auditory, and/or kinesthetic cues, attending to object, person or event pointed to by adult, understanding a few simple one word commands, understanding a few words referring to familiar objects, responding to inhibitory words, responding to name or name sign, and expressing some wants or needs through simple gestures or vocalizations (other than crying). The following skills are emerging: imitating a new

behavior similar to one in his repertoire while it is being performed by an adult, using a variety of objects in a way indicating knowledge of their function, using gestures or specific vocalizations to represent occurring/visible objects or activities, imitating a new sequence of activities when each activity is part of the child's repertoire, understanding a simple 2-3 word request expressing a simple noun-verb relationship, copying movements or vocalizations of an adult while adult is doing them, and imitating a simple movement within his repertoire after adult has completed the movement. In September his skills were at the 6-9 month level, with scattered skills to 14 months. Now he is at 9 months, with scattered skills to 18 months.

He continues to show significant delays in all areas, especially in motor skills, vision skills, daily living skills, and cognition/communication skills. Relative strengths include socialization with adults and listening skills. Informally, the teacher has tried using photos as an expressive communication option with him. When they were first introduced he had no interest in them, and they were recently presented again. Items in his photo library are limited to favorite toys, including his Blues Clues doll and Lights and Sounds Piano. We had also tried giving him a switch-activated calling device to see if he would call for attention instead of hitting his head against the wooden posts of the family room couch. He instead began to call for attention using his voice or by approaching adults and formal data on the switch-call system was discontinued.

Technical Assistance:

Ongoing: Liaison between family, child development specialist, medical personnel and other service providers, and initiate referrals to CBO when system changes require family participation. Loan of toys related to IFSP goals and video/written materials for family training as requested. Help parents interpret ongoing vision and hearing reports. Make referrals or suggest referrals to other service providers. Attend IFSP and MDC meetings as requested by parents.

May 20, 1997: Audiological tests at Mona Kea suggests a mild, moderate, or severe hearing loss. PRC paid for initial visit, and then audiologist re-enrolled him in DSCC now that he had a diagnosed eligible condition. DSCC paid for future visits and equipment. Tests were repeated throughout the years to refine diagnosis and modify hearing aid use. Later he receives ear tubes which help clear conductive component of hearing loss due to frequent otitis media.

June 19, 1997 - Developmental therapist notes improved vision skills, so another functional vision assessment is completed. He has improved ability to take in visual information but still qualifies for services.

September 12, 1997 - He and father and deafblind specialist go to Illinois College of Optometry for a PRC funded low-vision appointment - DSCC will not pay for low-vision services. Visual acuity is better defined and a prescription for glasses given. Family decided to pass on glasses as hearing aids are pulled out frequently.

September, 1997 - Family decides to drop other developmental therapy service due to new Family Fees requirement. He now gets

developmental from Philip Rock Center, and OT PT SLP from a private provider funded by DSCC.

July 1998 Entire family attends PRC Family Weekend.

September 1998 - New EI policy requires he get independent case manager (PRC does not provide these services). Developmental Evaluation completed and referral to Child and Family Connections facilitated.

NOW: Most current audiogram shows improved response to sound, with a sloping hearing loss (unaided =) from 25 to 40 dB in speech frequencies. He is aware of speech at 25 dB but may be missing out on some of the components of speech. He now responds, however, to several words such as his name and "no". PRC funds another low vision appointment July 1999 to assist with transition to school services. Reports to close EI services submitted

VI. Implications/Recommendations

The Illinois Project continues to work to: a) increase state capacity to improve services and outcomes for children who are deaf-blind and their families; b) assist in the development and operation of effective local programs for serving children who are deaf-blind; c) implement research-based effective practice that results in appropriate assessment, placement, and support services to all children who are deaf-blind in Illinois; d) offer service providers and families training opportunities for the necessary skills and knowledge areas to increase effective service to serve children who are deaf-blind; and e) provide a more accurate child count and tracking system for children and youth.

Individuals who are deaf-blind have unique needs that generate educational concerns. These educational concerns are amplified by the national need for teachers with qualifications and experiences related to learners who are deaf-blind (McLetchie and MacFarland, 1995). This shortage will be more keenly felt as more students are educated in inclusive general education settings, spreading teachers and related service personnel with experience in deaf-blindness even more thinly (Giangreco et al, 1997). As each child's educational plan is developed, educational teams and systems must carefully consider issues related to service integration and those practices, proven effective by research, shown to facilitate learning in inclusive and natural settings. However, assessing systems, programs and individual child progress is complicated by the irrelevance of many frequently used educational assessment and evaluation tools when applied to youth who are deaf-blind (Goetz, 1999). One technique shown effective in building local capacity, encouraging systems change and improving educational opportunities for youth who are deaf-blind is technical assistance.

OSEP should continue to promote incentives to increase the pool of qualified teachers and the ability of states to offer specialized technical assistance.

VII. Appendices

Chart A – Summary for Specialists' Activities

Chart B – State Geographic Assignments for Specialists

"together for independence"

PHILIP J. ROCK CENTER AND SCHOOL

Serving Individuals Who are Both Auditorilly and Visually Impaired
818 DuPage Blvd., Glen Ellyn, IL 60137
(630) 790-2474 & Fax: (630) 790-4893
(800) 771-1158 & TTY: (800) 771-1232

SUMMARY FOR SPECIALISTS' ACTIVITIES FOR
October 1994 - September, 1999

CHART A

	PROFESSIONAL	PARAPROFESSIONAL	FAMILY MEMBER
I. CONSULTATIVE SERVICES			
A. # of technical assistance contacts 0-3			
B. # technical assistance contacts 3-21			
TOTAL CONSULTATIVE SERVICES	**1,916**	**472**	**1,864**
II. TRAINING			
A. Number of people inserviced	**704**	**184**	**894**
III. INFORMATION/REFERRAL SERVICES			
A. Phone consultations			
B. Materials requests (photocopies or loans)			
TOTAL INFORMATION REFERRAL	**2,196**	**28**	**960**

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CHART B

State Geographic Assignments for Specialists -

Area I
Northeast = [134]
FTE 1.00 Michelle Clyne

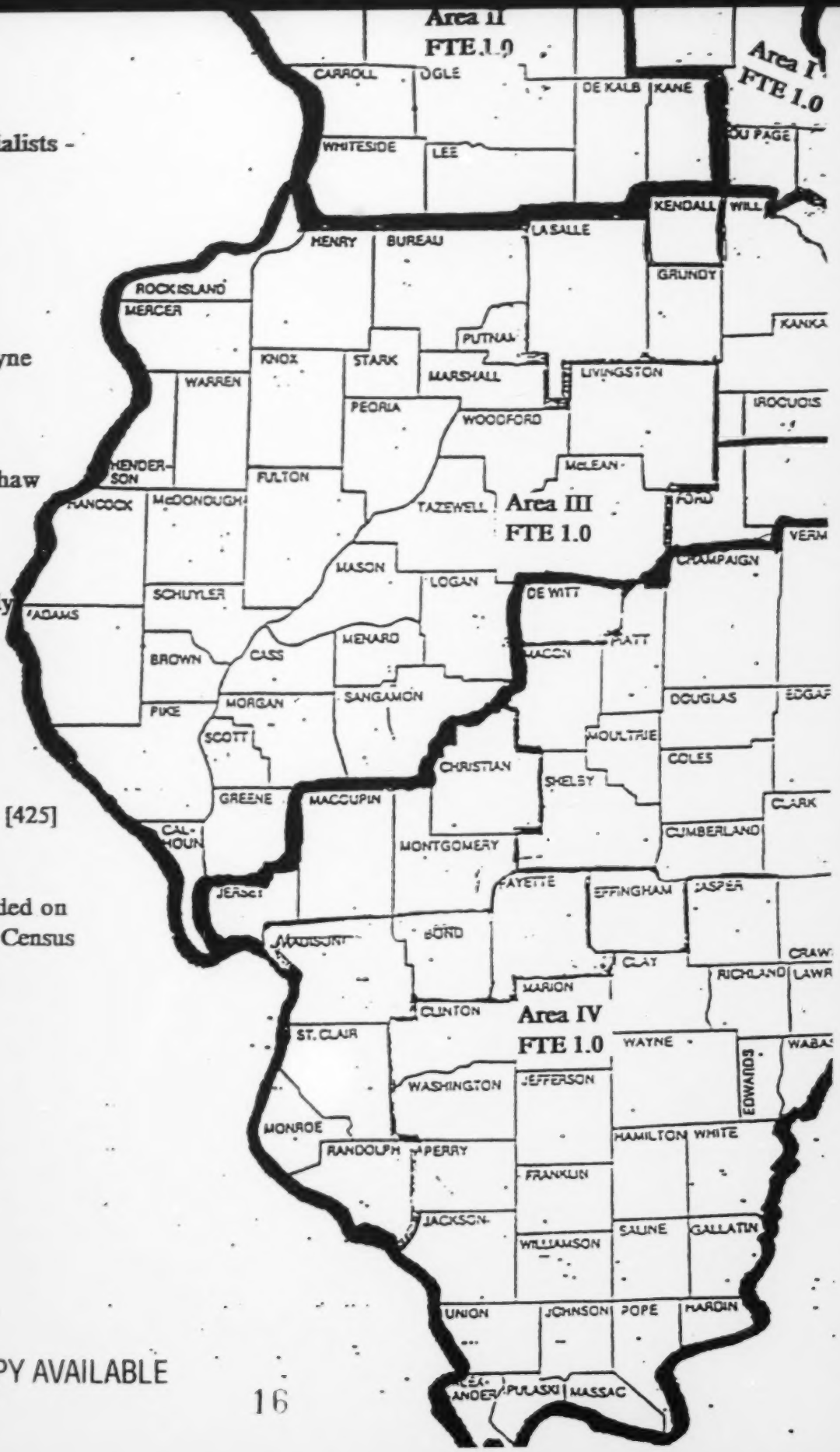
Area II
Northwest = [96]
FTE 1.00 Marybeth Shaw

Area III
Central = [110]
FTE 1.00 Karen Windy

Area IV
South = [85]
FTE 1.00 Carla Beck

Total # of Children = [425]

KEY
[ ] # of children recorded on the Illinois Deaf-Blind Census



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